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Prevalence of HIV-related stigma among people with HIV in Switzerland: Addressing the elephant in the room

Eleftheria KAMPOURI, José DAMAS, Katharina KUSEJKO, Bruno LEDERGERBER, Dominique BRAUN, Olivier NAWEJ TSHIKUNG, Anna HACHFELD, Maja WEISSER, Kerstin WISSEL, Enos BERNASCONI, Isabel COBOS MANUEL, David JACKSON-PERRY, Lars E. ERIKSSON, Maria REINIUS, Matthias CAVASSINI, Katharine E.A. DARLING, and the Swiss HIV Cohort Study (SHCS)

Eleftheria KAMPOURI, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland, Eleftheria-evdokia.kampouri@chuv.ch

José DAMAS, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland, Jose.Damas-Fernandez@chuv.ch

Katharina KUSEJKO, Division of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, Zurich, Switzerland, Katharina.Kusejko@usz.ch

Bruno LEDERGERBER, Division of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, Zurich, Switzerland, ledergb@gmail.com

Dominique BRAUN, Division of Infectious Diseases and Hospital Epidemiology, University Hospital Zurich, Zurich, Switzerland, Dominique.Braun@usz.ch

Olivier NAWEJ TSHIKUNG, Infectious Diseases, University Hospital Geneva, University of Geneva, Geneva, Switzerland, olivier.nawejtshikung@hcuge.ch

Anna HACHFELD, Department of Infectious Diseases, Bern University Hospital, University of Bern, Bern, Switzerland, anna.hachfeld@insel.ch

Maja WEISSER, Division of Infectious Diseases and Hospital Epidemiology, University Hospital Basel, University of Basel, Basel, Switzerland, maja.weisser@usb.ch

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Kerstin WISSEL, Division of Infectious Diseases and Hospital Epidemiology, Cantonal Hospital St. Gallen, St. Gallen, Switzerland, kerstin.wissel@cpzh.ch

Enos BERNASCONI, Division of Infectious Diseases, Ente Ospedaliero Cantonale, Lugano, University of Geneva and University of Southern Switzerland, Lugano, Switzerland, enos.bernasconi@eoc.ch

Isabel COBOS MANUEL, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland, Isabel-Maria.cobos@chuv.ch

David JACKSON-PERRY, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland, David.Jackson-Perry@chuv.ch

Lars E. ERIKSSON, Karolinska Institutet, Division of Nursing, Department of Neurobiology, Care Sciences and Society, Stockholm, Sweden, and School of Health and Psychological Sciences, City, University of London, London, United Kingdom, lars.eriksson@ki.se

Maria REINIUS, Karolinska Institutet, Division for Medical Management Centre, Department of Learning, Informatics, Management and Ethics, Stockholm, Sweden, maria.henrietta@gmail.com

Matthias CAVASSINI, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Switzerland, Matthias.Cavassini@chuv.ch

Katharine E.A. DARLING, Infectious Diseases Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland, Katharine.Darling@chuv.ch

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Corresponding author

Katharine E.A. DARLING, MD PhD

Katharine.Darling@chuv.ch

+ 41 21 314 1111

Infectious Diseases Service,

Lausanne University Hospital

Rue du Bugnon 46,

1011 Lausanne, Switzerland

Short running title: HIV-stigma in Switzerland

ABSTRACT

Objectives: We aimed to determine the prevalence of HIV-related stigma among people with HIV (PWH) in Switzerland

Design: A cross-sectional multicentre study nested within the Swiss HIV Cohort Study (SHCS).

Methods: We included adult PWH enrolled in the SHCS, attending follow-up between March 1st, 2020, and January 31st, 2021. Inability to speak English, French, German, or Italian was the only exclusion criterion. Participants were invited to complete a validated 12-item HIV-stigma questionnaire comprising four stigma subscales (negative self-image, personalised stigma, disclosure concerns, and concerns regarding public attitudes), plus two healthcare-related stigma items. Questionnaire responses were graded using a four-point Likert-type scale, higher scores indicating higher stigma. "Non-applicable", inferring HIV-status non-disclosure, was possible for personalised stigma; stigma scores from participants answering "non-applicable" to ≥1 items were analysed separately. Factors associated with HIV-stigma were identified through multivariable linear models.

Results: Of 9643 PWH with a SHCS visit, 5563 participated in the study: 26% were female, 13% Black and 37% heterosexual; median age was 53 years (interquartile range 44–59); 2067 participants (37%) gave ≥1 "non-applicable" responses. Disclosure concerns had the highest stigma scores and were reported by 4656/5563 (84%). HIV-stigma was reported across all demographic groups. However, being female, Black, and heterosexual were independently associated with higher scores. Higher education and longer follow-up duration were associated with lower scores. Healthcare-related stigma was reported in 37% of participants.

Conclusions: HIV-stigma was prevalent across all demographic groups. The association with being female and Black suggests that HIV-stigma accentuates pre-existing gender and race inequalities.

Keywords: HIV, stigma, 12-item scale, healthcare-related stigma, cohort

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INTRODUCTION

At the 42nd session of the United Nations General Assembly in 1987, Jonathan Mann, Director of the World Health Organisation Special Programme on AIDS, presented AIDS as three global epidemics: the epidemic of the AIDS virus (HIV), the epidemic of the AIDS disease and the epidemic of the social reaction to AIDS. The third epidemic, the social reaction to AIDS, was considered "as central to the global AIDS challenge as the disease itself".[1] Since the 1980s, prevention strategies and increasingly efficacious antiretroviral therapy (ART) have enabled great strides in tackling HIV and AIDS. The social reaction on the other hand, which includes HIV-related stigma, remains a global challenge.[2]

The HIV-stigma framework of Earnshaw and Chaudoir proposes mechanisms through which stigma may be experienced by people with HIV (PWH). These include enacted stigma, referring to discrimination experienced by the individual, anticipated stigma, referring to the awareness of negative social perception towards HIV and the expectation of prejudice and discrimination in the future, and internalized stigma, referring to an individual's endorsement of perceived negative beliefs.[3] Limitations of this framework include not addressing the intersectionality of stigma experienced by individuals possessing other socially devalued characteristics, and not accounting for changes in HIV-stigma over time or in different cultural and societal contexts.[3,4]

HIV-stigma negatively impacts the physical and psychosocial well-being of PWH at multiple levels. It can lead to late HIV presentation by hindering HIV testing, linkage to care and ART initiation.[5,6] According to 2020 figures, 97% of PWH in Switzerland engaged in care and enrolled in the Swiss HIV Cohort Study (SHCS) are receiving ART and 99% of those on ART have suppressed plasma HIV RNA.[7] However, late presentation in Switzerland, defined as having a CD4 count <350 cells/ml or an AIDS-defining condition at HIV diagnosis, accounted for 59% of all new diagnoses in one Swiss centre, suggesting that barriers to testing and/or linkage to care exist, despite good healthcare provision.[8] Further, distinct stigma mechanisms can differentially impact health outcomes. For example, internalized stigma is associated with depression among PWH and anticipated stigma with lower ART adherence.[9] [10–12] HIV-stigma also influences HIV-transmission behavioural parameters, including alcohol consumption.[11,13,14] HIV-stigma is thus a barrier to every step of the HIV care continuum including the 95-95-95 targets proposed by the Joint United Nations Program on HIV and AIDS (UNAIDS).[15,16] Quantifying HIV-stigma prevalence is a first step in determining the magnitude and form of this problem to address it. We aimed to quantify HIV-stigma among PWH enrolled in the SHCS and to identify associations between stigma and participant characteristics.

METHODS

Study design and setting

We performed a national multicentre cross-sectional study within the SHCS (https://www.shcs.ch/). The SHCS is a multicentre, prospective cohort study established in 1988, enrolling adult PWH in Switzerland from seven participating centres (Basel, Bern, Geneva, Lausanne, Lugano, St. Gallen, and Zurich), affiliated hospitals and private physicians.[17] For all SHCS-enrolled PWH, detailed demographical, clinical and biological data are collected at registration and then at twice-yearly follow-up visits.[17] The SHCS was approved by the local ethics committees of all participating study sites. All participants signed informed consent prior to inclusion.

Participants

All adult PWH enrolled in the SHCS were eligible for inclusion. The only exclusion criterion was insufficient fluency in English, French, German, or Italian to be able to complete the study questionnaire. Fluency level was judged by the treating HIV physician and was considered insufficient if participants 1) did not understand the word or concept of "stigma" and 2) were unable to answer one or more questions through lack of vocabulary.

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Questionnaire

HIV-stigma was quantified using a validated 12-item questionnaire developed by Reinius *et al*,[18] an abbreviated version of the 40-item HIV-stigma scale of Berger *et al*.[19] The questionnaire evaluates three items for each of four stigma subscales: negative self-image, personalised stigma, disclosure concerns, and concerns regarding public attitudes (Table S1, http://links.lww.com/QAD/D292). Responses are graded using a four-point Likert-type scale scoring system (1: strongly disagree, 2: disagree, 3: agree, 4: strongly agree), where higher scores indicate higher stigma. The 12-item questionnaire has been reported to be less sensitive than the longer (40-item) scale but has comparable psychometric properties.[18] We chose the 12-item version so that completing the questionnaire would be feasible during a clinic visit, optimising participation rates and procedure uniformity. As there were no standardised measuring tools for assessing healthcare-related HIV-stigma at the time of our study,[20] we developed and added one question examining enacted stigma ("Have you ever felt discriminated against through having HIV when receiving medical care?") and one examining anticipated stigma ("Are you worried that your HIV status might be divulged by medical personnel to others?"), providing the four-point Likert-type scale scoring system above (Table S1, http://links.lww.com/QAD/D292). At the end of the 14 items, we invited the participants to evaluate the stigma questionnaire experience, again using the four-point Likert-type scale scoring system, with the question, "I'm glad to have been able to discuss this subject with my doctor today" (Table S1, http://links.lww.com/QAD/D292). The questionnaire was translated and back-translated from English to the three official Swiss languages, German, French, and Italian, by healthcare professionals with native-level fluency in the relevant languages.

Procedures

Participants were invited to complete the questionnaire, which was embedded in the SHCS follow-up pro forma, at their semi-annual SHCS visit with their assigned HIV physician. As this study coincided with the start of the SARS-CoV-2 pandemic, questionnaires were completed either face-to-face or by telephone during a structured interview. Participants' answers were registered by the interviewer on the SHCS online platform. After conducting a pilot study, the study was expanded to all SHCS sites from July 1st, 2020, until January 31st, 2021 (Supplement, http://links.lww.com/QAD/D292). During the pilot study we observed that some participants were unable to respond to items in the personalised stigma subscale as they implied HIV-status disclosure (Table S1, http://links.lww.com/QAD/D292). When participants had not discussed their HIV status with anyone other than HIV centre staff, we introduced the option, "non-applicable" (NA), without assigning a score. For analysis, participants with ≥1 NA response to personalised stigma items were categorised as "HIV undisclosed" and participants without NA answers as "HIV disclosed".

Definitions and outcomes

Definitions are detailed in the Supplement. The HIV-stigma score was examined for the 12 validated questions as total score (possible score 12 to 48), score per stigma subscale (possible score 4 to 12) and score for healthcare-related stigma (possible score 2 to 8). Cronbach's alpha was assessed for the subscales to ensure internal consistency and was considered acceptable if >0.7.[21] To account for

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language differences, we performed sub-analyses for the German-speaking centres, and for centres with Latin-root languages (French and Italian). Stigma was analysed first as a continuous variable taking average stigma score. For personalised stigma items, which provided the option "NA", we calculated average scores based on the number of questions answered. In this way, participants who responded "NA" to <3 items in the personalised stigma subscale retained measurable scores for other questions within the subscale. Stigma was also analysed as a binary variable, taking "agree" and "strongly agree" to any of the three items to indicate stigma. Analyses were performed for all participants, and then separately for "HIV disclosed" and "HIV undisclosed". Participants having missing values in any of the variables of interest were excluded from analysis.

Statistical analyses

Descriptive analyses are presented as mean (standard deviation, SD) for symmetric continuous variables, median (interquartile range, IQR) for asymmetric continuous variables and as percentages for categorical variables. We used linear regression models to evaluate risk factors for the outcomes of interest (variables in **Table 1** and detailed in the Supplement, http://links.lww.com/QAD/D292). Our outcomes of interest were average total score (12-item), and average score for each of the stigma subscales (for all participants, and for "HIV disclosed" and "HIV undisclosed"). We evaluated the two healthcare-related stigma items separately as they were not part of the validated 12-item questionnaire and as we observed low internal consistency in a preliminary analysis (**Table S2**, http://links.lww.com/QAD/D292). In univariable analyses, the factors associated with stigma outcomes were similar when analysing stigma for all 12-items (average total score) and when analysing by each subscale. For this reason, we present our results only for total average scores. Multivariable linear regression models were built manually, adding clinical, demographic, and other baseline characteristics of interest, and those with a P value of <0.05 in univariable analysis. Statistical significance was set at P value ≤0.001 after Bonferroni adjustment. The final model was selected based on Akaike and Bayesian information criteria. We used Stata SE 17.0 (StataCorp, College Station, TX) for all analyses.

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RESULTS

Participants

Between March 1st, 2020, and 31st January 31st, 2021, a total of 9643 participants had at least one of their semi-annual SHCS visits. The HIV-stigma questionnaire was completed by 5794 (60%) participants. Of these, 158 participants completed the questionnaire after the study period and 73 had missing values in variables of interest and were excluded. Information regarding why participants did not answer the questionnaire could not be retrieved from the SHCS. People answering the questionnaire were more likely to be younger, white and to have undetectable viral loads and higher levels of education. There were no differences in terms of sex and most likely mode of HIV acquisition. In total, 5563 participants were included in the study of whom 2067 (37.2%) responded NA to ≥1 of the three personalised stigma items ("HIV undisclosed") (**Table 1**). "HIV undisclosed" were more often women (32.8% in the "HIV undisclosed" group versus 22.6% in the "HIV disclosed" group), Black (19.4% vs 9.9%), heterosexual (49.3% vs 29.4%), with lower educational level (up to mandatory education in 32.8% vs 15.5%) and living with family/children (19.2% vs 12%) (**Table 1**).

The internal consistency of the 12-item questionnaire

The 12-item questionnaire had a Cronbach's alpha value of 0.81, which is acceptable. However, we observed variations between alpha values among subscales (Table S2, http://links.lww.com/QAD/D292), especially among negative self-image items where alpha values were <0.7. We measured loadings, which are the percentages of variance in all the variables related to the relevant factor (stigma subscale or stigma score overall). We explored loadings for each of the 12 items and observed that one specific item in the negative self-image subscale (*"I feel guilty because I have HIV"*) had low standardised loadings (<0.7) (Table S3, http://links.lww.com/QAD/D292). Loadings were lower among French and Italian speakers (0.66 and 0.61, respectively) in comparison to German speakers (0.73). Cronbach's alpha values for this item were <0.7 for all three languages (Table S2, http://links.lww.com/QAD/D292).

HIV-stigma scores

Among all participants, 89.1% reported stigma in at least one subscale. "Disclosure concerns" was the most prevalent stigma sub-scale (83.7%); 90.9% of all participants agreed with the item "I am very careful whom I tell that I have HIV". Personalised stigma and concerns regarding public attitudes followed with a prevalence of around 44%, and 37.3% of participants reported healthcare-related stigma. These findings are summarized in **Table 2** and **Figure 1**.

Median scores by stigma subscale and by participant demographic group are shown in Table S4, http://links.lww.com/QAD/D292. Among participants who had disclosed their HIV-status ("HIV disclosed"), the overall median (IQR) score was 25 (21–29) for the 12-item questionnaire (possible score 12 to 48) and 28 (24 to 33) for the 14-item (adding healthcare-related stigma) (possible score 14 to 56). Average score was 2.1 (SD, 0.5) and 2.1 (SD, 0.4) for the 12-item and 14-item questionnaire among "HIV disclosed" participants versus 2.6 (SD, 0.5) and 2.5 (SD, 0.4) among "HIV undisclosed" participants (Table S5, http://links.lww.com/QAD/D292). Disclosure concerns was the highest-rated stigma subscale in both "HIV disclosed" and "HIV undisclosed" with an average score of 3 (SD 0.7) and 3.6 (SD 0.5), respectively, followed by concerns about public attitudes, healthcare-related stigma, negative self-image, and personalised stigma. "HIV undisclosed" participants had higher average scores in all stigma subscales than "HIV disclosed" participants ($P < 0.0001$) (Table S5, http://links.lww.com/QAD/D292**; Figure 2D**).

Factors associated with higher HIV-stigma scores

In the multivariable analysis, being heterosexual female (β: 0.28 95% CI: 0.24 to 0.32), heterosexual male (β: 0.19, 95% CI: 0.15 to 0.23), and having "other" as most likely mode of HIV acquisition (β: 0.11, 95% CI: 0.05 to 0.18) were associated with higher average stigma scores compared to being MSM; Black (β: 0.23, 95% CI: 0.18 to 0.27) or Asian ethnicity (β: 0.19, 95 CI%: 0.11 to 0.27) was also associated with higher score compared to being White, as was the presence of neurocognitive

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complaints compared to their absence (β: 0.13, 95% CI: 0.07 to 0.18). A sensitivity analysis, creating a Black female and White female variable, demonstrated HIV-stigma in both cases and of slightly higher magnitude for the Black female group (β: 0.4 Black versus 0.1 White). Factors associated with lower mean average stigma scores were higher level of education versus mandatory education ($P \leq 0.01$), and longer time of enrolment in the SHCS (per 10 years of follow-up, ($P < 0.001$) (**Table S6, Figure 3**). Similar factors associated with higher or lower mean average stigma scores were observed upon analysis by sub-group ("HIV disclosed" and "HIV undisclosed"), with the exception of retired participants in the "HIV disclosed" subgroup who had lower mean scores (β: -0.12, 95 CI%: -0.19 to 0.05) compared to those currently employed (Table S6, http://links.lww.com/QAD/D292**, Figure 3**).

Finally, as HIV-stigma can be quantified but not 'seen', the heat maps in Figure 2 are an attempt to summarise visually HIV-stigma in key participant sub-groups and the change (or lack of change) with SHCS follow-up time. We observed a negative association between average stigma score and follow-up time, an association which varied with sex, origin, most likely mode of HIV acquisition, and HIV status disclosure (**Figure 2, A-D**).

DISCUSSION

In this large study of PWH under optimal care, HIV-stigma was prevalent across all demographic groups. Disclosure concerns was the subscale with the highest score and over a third of participants answered NA to ≥1 personalised stigma item due to HIV-status non-disclosure. Being female, Black, heterosexual (male or female), and having previous neurocognitive complaints and depression were associated with higher HIV-stigma scores. Higher educational level and longer duration of SHCS follow-up (> ten years) were associated with lower HIV-stigma scores. Overall, we found that the 12-item questionnaire performed well, was easily applicable during a standard HIV-clinic visit and was mostly welcomed by participants.

"Disclosure concerns" having the highest stigma score has been described in other studies.[18,22] Although HIV-stigma was prevalent among all participants, being female, Black, and heterosexual was consistently associated with higher stigma scores, both by subscale and overall. These characteristics were more frequent among participants in the "HIV undisclosed" sub-group. In a Canadian study among 1026 PWH, Black women consistently presented the highest stigma score and gender-ethnicity interaction was an independent factor for higher stigma in multivariable analyses.[23] In line with other European studies, the higher prevalence observed in female, Black, heterosexuals should be interpreted in the light of stigma intersectionality among migrants and related challenges in access to healthcare.[24,25] Further the high "non-disclosure" rates and fear of non-acceptance in these subpopulations lead to lack of community which is key for well-being.[24,25]

Neurocognitive complaints and depression were also associated with higher stigma scores. Expressing neurocognitive complaints for all three EACS screening questions has previously been shown to be significantly associated with depression and imperfect ART adherence in the SHCS.[26,27] In our study, 158 of 396 participants (40%) with neurocognitive complaints also had depression, suggesting a cofactor effect between the two variables. The deleterious association between HIV-stigma and depression has been described in a series of meta-analyses.[11] In a study

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in Florida, PWH with severe depression and disability were almost three times more likely to report HIV-stigma.[28] Disability in this particular study included difficulties in remembering, concentrating, and making decisions which broadly correspond to the EACS neurocognitive impairment screening questions on memory, attention and mental slowing. Finally, higher educational level and longer duration of SHCS follow-up were independently significantly associated with lower stigma, as previously described.[14,23]

Earlier studies report a negative impact of HIV-stigma on ART adherence and plasma HIV viral load.[10,12,23,29] In our study, detectable plasma HIV RNA was associated with higher HIV-stigma in the univariable but not in the multivariable analysis. HIV RNA and ART adherence were not significantly different between the "HIV disclosed" and "HIV undisclosed" sub-groups. However, it should be noted that <5% of the participants in our study presented detectable viral loads, thus limiting the capacity to detect a meaningful association. Our findings agree with a recent study by Reinius *et al.* reporting no relation between stigma and ART adherence, measured by the surrogate of detectable plasma HIV RNA.[30]

Late presentation to care was observed in 47.3% of the participants, a figure similar to previous SHCS estimates in 2009–2012 (49.8%).[8,31] Even though an association between late presentation with higher overall HIV-stigma scores was present in univariable analysis, this was lost after adjusting for confounders. Finally, healthcare-related stigma can be an obstacle to HIV prevention, treatment access and retention in care.[32–34] In our study, healthcare-related stigma was reported by over 37% of participants who agreed with at least one question in this subscale. The degree of healthcare-related stigma is insufficiently reported in the literature, in part due to the lack of standardised specific measurement tools.[20]

Our study has limitations. The cross-sectional design precludes establishing causal associations. The reason(s) for not completing the questionnaire was not collected. While the questionnaire performed well overall, we observed variation in Cronbach's alpha values among subscales, with a low value in the negative self-image subscale and the *"I feel guilty because I have HIV"* item in particular. This differed between French/Italian speakers in comparison to German speakers. It is plausible that the translation of the questionnaire (notably of the word "guilty") and other unquantifiable cultural differences reflected in language contributed to this finding. The main outcome (HIV-stigma) and measures such as neurocognitive complaints and ART adherence were self-reported, potentially engendering recall and/or social desirability bias. Although our study sample was representative of PWH in Switzerland, some key populations, for example, people who inject drugs and transgender individuals, are also minority populations. In this way, our results may not be applicable to other settings. Finally, this was a quantitative study and findings from qualitative studies are needed to inform the design of interventions and healthcare policies.[35]Against these limitations, we used a validated HIV-stigma scale to quantify stigma and our study is the largest HIV-stigma prevalence study to date, one of relatively few in Europe and the first in Switzerland.

The SHCS was established in the year after Jonathan Mann described the "social reaction" to AIDS,[1,17] and yet it is only now that we present the first formal quantification of stigma prevalence in Switzerland. It is striking to observe high stigma scores in the era of modern ART, in a resource-

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rich country where life expectancy is excellent [36] and when undetectable plasma HIV RNA equals non-transmissibility.[37] This study has been necessary, even at this late stage in the HIV/AIDS pandemic, to quantify the magnitude and distribution of HIV-stigma.

CONCLUSIONS

In conclusion, we have observed that HIV-stigma is prevalent in Switzerland. Female, Black, and heterosexual individuals reported higher stigma, suggesting pre-existing gender and race inequalities. However, stigma was prevalent across all demographic groups. Quantifying HIV-stigma was feasible during follow-up visits and facilitated conversations between PWH and clinicians about this under-discussed subject and "elephant in the room" (Figure S1, http://links.lww.com/QAD/D292).

Authorship Contributions:

EK, MC, KEAD contributed to the study conception, study design, study performance, study management, data analysis, data interpretation, and manuscript writing. JD contributed to data analysis and interpretation, manuscript writing and critical review of the manuscript. KK was responsible for implementing the stigma questionnaire in the SHCS online platform, and data management. All authors contributed to the study performance and critical review of the manuscript. EK and KEAD are study guarantors, accept full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. The corresponding author attests that all listed authors meet authorship criteria and that no other meeting the criteria have been omitted.

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Members of the Swiss HIV Cohort Study

Abela I, Aebi-Popp K, Anagnostopoulos A, Battegay M, Bernasconi E, Braun DL, Bucher HC, Calmy A, Cavassini M, Ciuffi A, Dollenmaier G, Egger M, Elzi L, Fehr J, Fellay J, Furrer H, Fux CA, Günthard HF (President of the SHCS), Hachfeld A, Haerry D (deputy of "Positive Council"), Hasse B, Hirsch HH, Hoffmann M, Hösli I, Huber M, Jackson-Perry D (patient representatives), Kahlert CR (Chairman of the Mother & Child Substudy), Keiser O, Klimkait T, Kouyos RD, Kovari H, Kusejko K (Head of Data Centre), Labhardt N, Leuzinger K, Martinez de Tejada B, Marzolini C, Metzner KJ, Müller N, Nemeth J, Nicca D, Notter J, Paioni P, Pantaleo G, Perreau M, Rauch A (Chairman of the Scientific Board), Salazar-Vizcaya L, Schmid P, Speck R, Stöckle M (Chairman of the Clinical and Laboratory Committee), Tarr P, Trkola A, Wandeler G, Weisser M, Yerly S.

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Conflicts of Interest Disclosures

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Ethics Approval Statement:

The SHCS was approved by the local ethics committees of all participating study sites (*Ethikkommission Nordwest- und Zentralschweiz EKNZ* in Basel, *Kantonale Ethikkommission* Bern in Bern, *Commission Cantonale d'Ethique de la Recherche sur l'être humain* in Geneva, *Commission cantonale d'éthique de la recherche sur l'être humain* in Lausanne, *Comitato etico cantonale* in Bellinzona, *Ethikkommission Ostschweiz EKOS* in St. Gallen and *Ethikkommission Zürich* in Zurich).

Patient and Public Involvement statement: A patient expert was a member of the research team and involved in the study design and critical review of the manuscript. While the authors are aware that this constitutes public engagement rather than PPI, part of this study was presented at a public forum entitled, "*Une maladie comme une autre?*" (translated as, "An illness like any other?") to mark World AIDS Day, 1st December 2020: https://www.chuv.ch/fr/min/min-home/patients-et-familles/consultation-ambulatoire/lantenne/conference-une-maladie-chronique-comme-une-autre-1

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Figure 1 (Title): Prevalence of HIV-related stigma

Prevalence of HIV-related stigma by subscale among different demographic groups. MSM: men who have sex with men, PWID: people who inject drugs, TGW: transgender women.

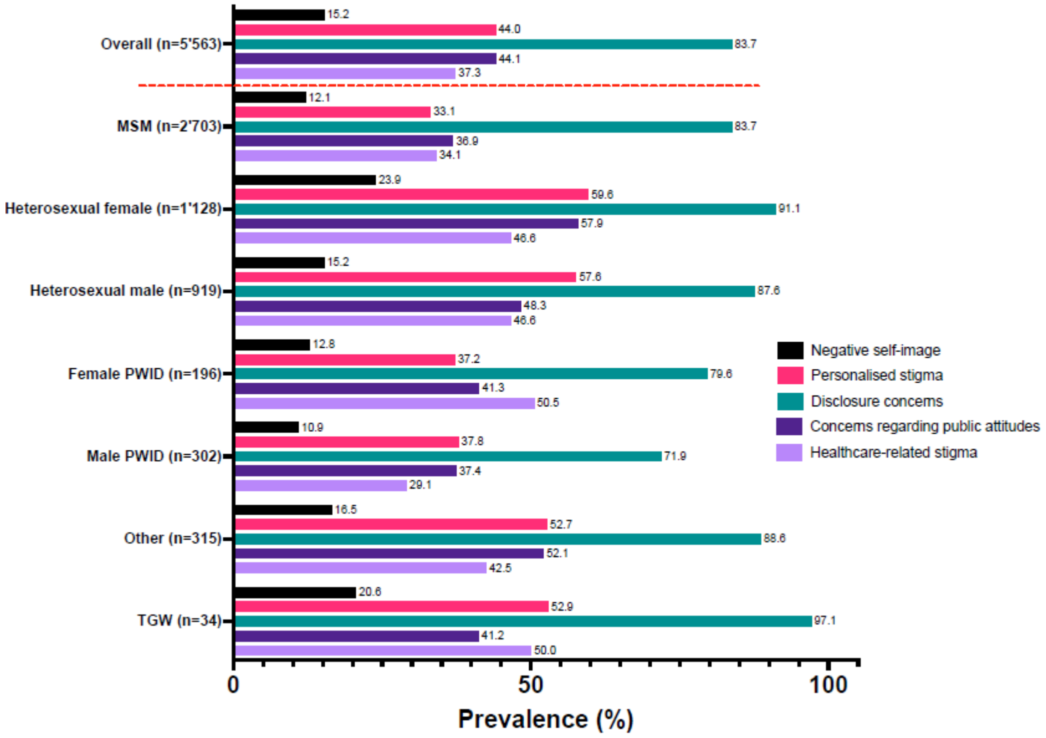


Figure 2 (Title): Heat maps of average stigma scores by time of follow-up within the Swiss HIV Cohort Study

The intensity of colour represents mean HIV-stigma average scores. Values over two (2) indicate stigma and are characterized by darker colours. Stigma scores are depicted for different demographic groups (x axis) based on follow-up time in years at the SHCS (y axis). Panels depict scores categorised by: sex (**A**), ethnicity (**B**), most likely mode of HIV acquisition (**C**), and HIV disclosed (= disclosed to at least one friend or family member) and undisclosed (**D**). MSM: men who have sex with men, HET: heterosexual (M: male, F: female), PWID: people who inject drugs (M: male, F: female).

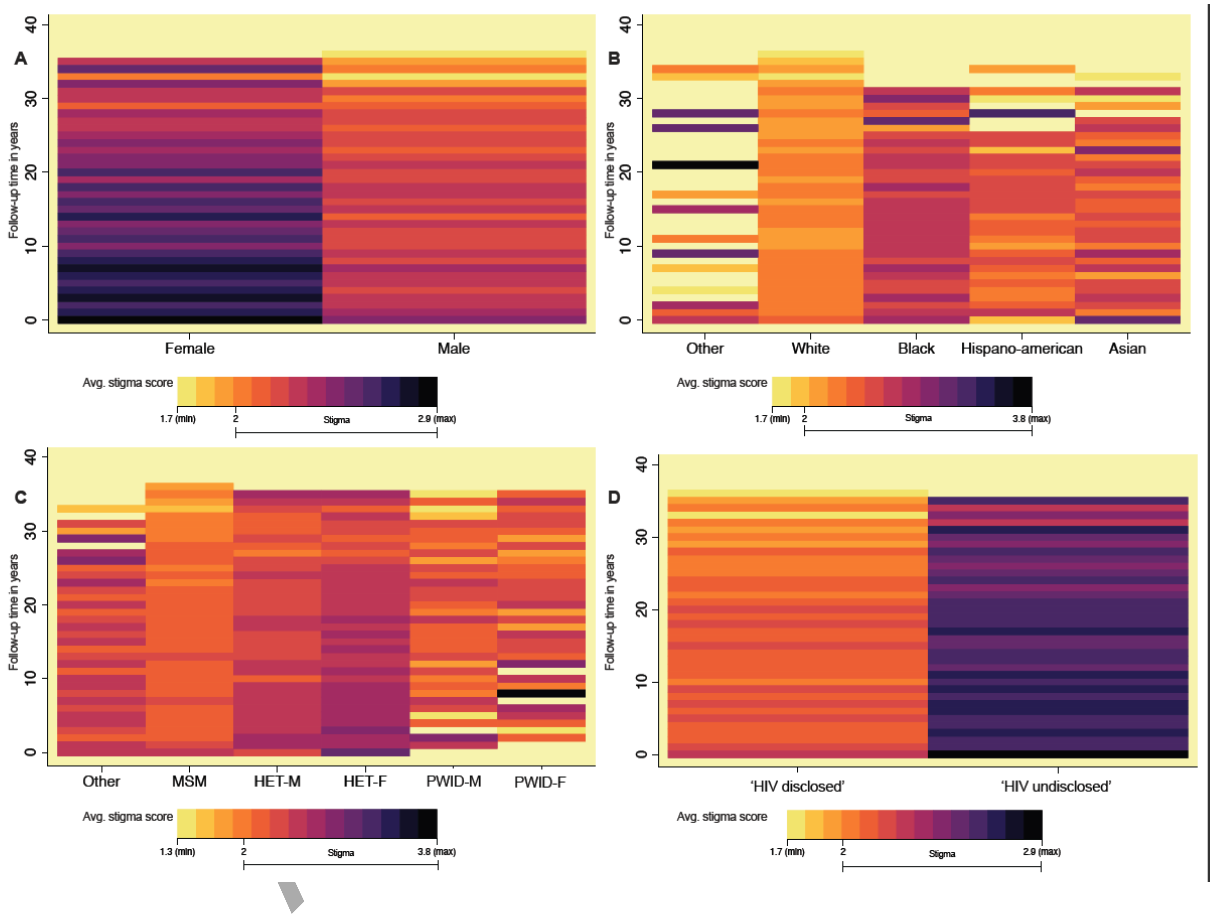
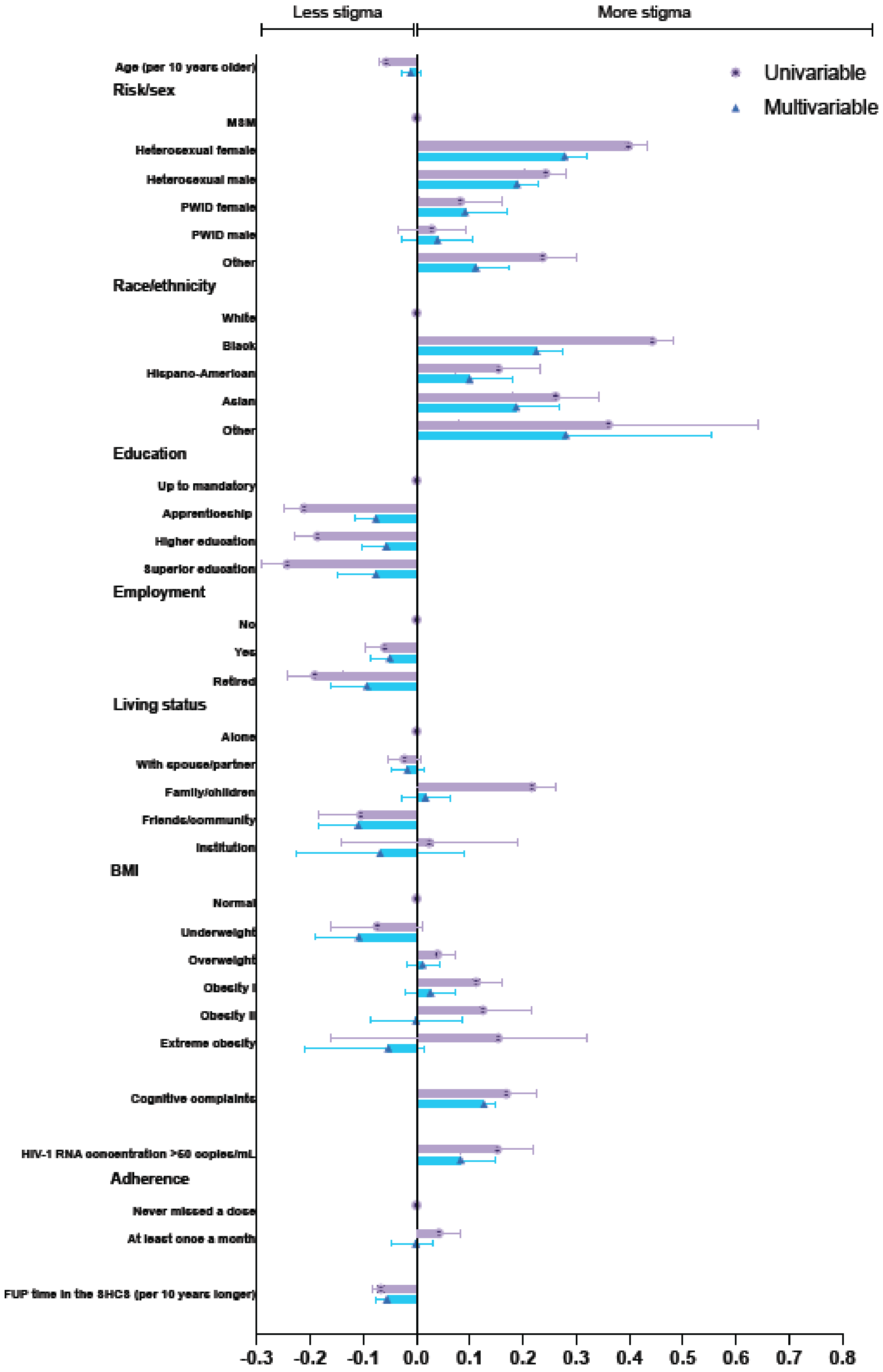


Figure 3 (Title): Forest plot of univariable and multivariable models for HIV-relate stigma

Forest plot with coefficients and 95% confidence intervals for factors associated with HIV-related stigma average scores. Circles correspond to univariable and triangles to multivariable models. BMI: body mass index; FUP: follow-up time; PWID: people who inject drugs; MSM: men who have sex with men. BMI definitions: normal = BMI 18.5-24.9; underweight = BMI <18.5; overweight = BMI 25-29.9; obesity I = BMI 30-34.9; obesity II = 35-39.9; extreme obesity = BMI ≥40)



Less stigma
More stigma
Univariable
Multivariable
Age (per 10 years older)
Risk/sex
MSM
Heterosexual female
Heterosexual male
PWID female
PWID male
Other
Race/ethnicity
White
Black
Hispano-American
Asian
Other
Education
Up to mandatory
Apprenticeship
Higher education
Superior education
Employment
No
Yes
Retired
Living status
Alone
With spouse/partner
Family/children
Friends/community
Institution
BMI
Normal
Underweight
Overweight
Obesity I
Obesity II
Extreme obesity
Cognitive complaints
HIV-1 RNA concentration >50 copies/mL
Adherence
Never missed a dose
At least once a month
FUP time in the SHCS (per 10 years longer)
-0.3
-0.2
-0.1
0.0
0.1
0.2
0.3
0.4
0.5
0.6
0.7
0.8

Table 1. Characteristics of participants.

	All participants (n= 5563)	"HIV disclosed" sub-group (n=3496)	"HIV undisclosed" sub-group (n=2067)	P
Socio-demographic factors:				
Age, median (IQR)	53 (44, 59)	53 (44, 59)	53 (45, 60)	
Female sex, n (%)	1468 (26.4)	790 (22.6)	678 (32.8)	<0.0001
Employment				0.005
Employed, n (%)	3577 (64.3)	2253 (64.5)	1324 (64.1)	
Retired	782 (12.6)	406 (11.6)	296 (14.3)	
Education				<0.0001
Superior education, n (%)	823 (14.8)	270 (13.1)	553 (15.8)	
Higher education, n (%)	1208 (21.7)	792 (22.65)	416 (20.1)	
Apprenticeship, n (%)	2314 (41.6)	1474 (42.16)	840 (40.6)	
Up to mandatory education, n (%)	1218 (21.9)	541 (15.5)	677 (32.8)	
Household composition:				<0.0001
Living alone, n (%)	2315 (41.6)	1516 (43.4)	799 (38.7)	
Living with spouse/partner, n (%)	2178 (39.1)	1373 (39.3)	805 (38.9)	
Living with family/children, n (%)	817 (14.7)	420 (12)	397 (19.2)	
Living with friends/community, n (%)	210 (5.7)	154 (4.4)	56 (2.7)	
Living in a social institution, n (%)	43 (0.8)	33 (0.9)	10 (0.5)	
Race/ethnicity:				<0.0001
White, n (%)	4451 (80.1)	2.935 (84)	1516 (73.3)	
Black, n (%)	746 (13.4)	346 (9.9)	400 (19.4)	
Hispano-American, n (%)	182 (3.3)	120 (3.4)	62 (3)	
Asian, n (%)	170 (3.1)	87 (2.5)	83 (4)	
Other, n (%)	14 (0.3)	8 (0.2)	6 (0.3)	
Most likely mode of HIV-acquisition:				<0.0001

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Men who have sex with men, n (%)	2703 (48.6)	1932 (55.3)	771 (37.3)	
Heterosexual, n (%)	2047 (36.8)	1027 (29.4)	1020 (49.3)	
PWID, n (%)	498 (8.9)	360 (10.3)	138 (6.7)	
Other/unknown, n (%)	315 (5.6)	177 (5.1)	138 (6.7)	
HIV parameters:				
HIV viral load < 50 copies/mm^3	5299 (95.3)	3339 (95.5)	1960 (94.8)	0.2
Current CD4 count, median (IQR)	690 (517, 897)	703 (530, 909)	670 (495, 870)	<0.0001
Nadir CD4 count, median (IQR)	227 (112, 350)	232 (116, 357)	219 (109, 340)	0.03
AIDS, n (%)	1154 (20.7)	725 (20.7)	429 (20.8)	0.9
Infection duration, years, median (IQR)	13 (7, 21)	13 (7, 21)	12 (6, 20)	<0.0001
On ART, n (%)	5490 (98.7)	3452 (98.7)	2038 (98.6)	0.6
Incomplete adherence, n (%)	834 (15)	548 (15.7)	286 (13.8)	0.04
Late presentation, n (%)	2631 (47.3)	1549 (44.3)	1082 (52.3)	<0.0001
Neuropsychological parameters:				
Depression, n (%)	694 (12.5)	485 (13.9)	209 (10.1)	<0.0001
Neurocognitive complaints, n (%)	396 (7.1)	254 (7.3)	142 (6.9)	0.5
Other medical and behavioural parameters:				
HCV, n (%)	785 (14.1)	547 (15.6)	238 (11.5)	<0.0001
Moderate/severe alcohol consumption, n (%)	902 (16.2)	633 (18.1)	269 (13)	<0.0001
Current cigarette smoking, n (%)	1798 (32.3)	1238 (35.4)	560 (27.1)	<0.0001
Injection drugs, n (%)	66 (1.2)	53 (1.5)	13 (0.6)	0.003
Non-injection drugs, n (%)	863 (15.5)	642 (18.4)	221 (10.7)	<0.0001

"HIV undisclosed" are participants who answered "non-applicable" to ≥ 1 personalised stigma item; "HIV disclosed" are participants who had disclosed HIV to other people and were able to rate the personalised stigma using the 4-item Likert-like scale.

Abbreviations: ART, antiretroviral therapy; HCV, hepatitis C virus; IQR, interquartile range; PWID, people who inject drugs; P value refers to the comparison between the "HIV undisclosed" and "HIV disclosed". Statistical significance was defined as a P value ≤0.001 using Pearson chi^2 test for categorical covariates and using nonparametric test for trend across groups continuous covariates.

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Table 2. Binary analysis of stigma

Stigma item	**All participants n=5757**	**“HIV disclosed” sub-group n=3496**	**“HIV undisclosed” sub-group n=2067**	**P**
Negative self-image				
I feel guilty because I have HIV	1121 (20.2)	603 (17.3)	618 (25.1)	<0.0001
I feel I am not as good a person as others because I have HIV	566 (10.2)	287 (8.2)	279 (13.5)	<0.0001
People's attitudes about HIV make me feel worse about myself	1575 (28.3)	893 (25.5)	682 (33)	<0.0001
Personalised stigma*				
People I care about stopped calling after learning I have HIV	445 (8.0)	387 (11)	58 (2.8)[1]	-
I have lost friends by telling them I have HIV	601 (10.8)	532 (15.2)	69 (11.5)[2]	-
Some people avoid touching me once they know I have HIV	559 (10.1)	436 (12.5)	123 (22)[3]	-
Disclosure concerns				
Telling someone I have HIV is risky	4356 (78.3)	2464 (70.5)	1892 (91.5)	<0.0001
I work hard to keep my HIV a secret	4107 (73.8)	2235 (63.9)	1872 (90.6)	<0.0001
I am very careful who I tell that I have HIV	5055 (90.9)	3042 (87)	2013 (97.4)	<0.0001
Concerns regarding public attitudes				
Most people believe that a person who has HIV is 'dirty'	2053 (36.9)	1163 (33.3)	890 (43.1)	<0.0001
Most people are uncomfortable around someone with HIV	2,938 (52.8)	1568 (44.9)	1,370 (66.3)	<0.0001
People with HIV are treated like outcasts	2495 (44.9)	1409 (40.3)	1086 (52.5)	<0.0001
Healthcare-related stigma				

Have you ever felt discriminated against through having HIV when receiving medical care?	1213 (21.8)	788 (22.5)	425 (20.6)	0.08
Are you worried that your HIV status might be divulged by medical personnel to others?	1347 (24.2)	706 (20.2)	641 (31)	<0.0001

Results represent number of participants who agree with each item, and percentage in parenthesis.

“Agree” and “Strongly agree” responses are grouped (score ≥ 3 = stigma, score < 3 = No stigma). The proportion of participants agreeing with each stigma item are presented for: i) all participants, ii) “HIV disclosed” (defined as participants without any “non-applicable” (NA) responses) and iii) “HIV undisclosed” (defined as participants with ≥ 1 NA response). The P values refer to the differences between “responders” and “non-responders”. Statistical significance was defined as a P value ≤0.001

*The “non-applicable” (NA) option is possible only for items in the personalised stigma subscale; in the “non-responders” group, NA answers are excluded (the number of participants for each item was: i) 511 participants, ii) 426, iii) 366

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